NOVA SCOTIA
Disabled Persons Commission

102-00895/

2000-01 Annual Report

Nova Scotia Disabled Persons Commission

September, 2001

Table of Contents

1. Message from the Chair ..... page 01

2. The Disabled Persons Commission
   - 2.1 Background ..... page 03
   - 2.2 Co-ordinating Committee of Ministers ..... page 04
   - 2.3 Commission Members ..... page 04

3. Disability in Nova Scotia
   - 3.1 Definition of Disability ..... page 06
   - 3.2 Profile of Disability in Nova Scotia ..... page 08

4. Disability Employment Tool Kit ..... page 11

5. Public Meeting - New Glasgow ..... page 12

6. Disability Web Links ..... page 13

7. Special Education Policy Implementation Review ..... page 14

8. Inclusive Transportation Initiative ..... page 16

9. Nova Scotia Access Awareness Week
   - 9.1 Proclamation Ceremony ..... page 17
   - 9.2 Citizenship Forum ..... page 17
   - 9.3 Mel Hebb Hourglass Action Awards ..... page 18

10. Nova Scotia Neurotrauma Initiative ..... page 19

11. Other Issues and Initiatives

11.1 Human Rights Commission Organizational Review ..... page 20
11.2 The Kendrick Report ..... page 21
11.3 Tracey Latimer ..... page 21
11.4 Access to Government Real Property ..... page 23
11.5 Employer Recognition/Team Work Cooperative Ltd. ..... page 23
11.6 Information and Referral ..... page 24

APPENDICES

A. New Glasgow Public Meeting ..... page 25
B. Winning Access Awareness Poster ..... page 33a
C. Workshop Report: Kendrick Review ..... page 34
Appendix A ..... page 48

1. MESSAGE FROM THE CHAIR

I am pleased to present the 2000-01 Annual Report of the Nova Scotia Disabled Persons Commission. The Report gives a brief overview of some of the issues and initiatives that have been on the Commission's agenda over the past year.

This marks the first Annual Report during my term as Chair of the Commission and I would like to take this opportunity to thank the previous Commission for their work on behalf of persons with disabilities. I would particularly like to acknowledge the leadership of Nita Irvine whose term of appointment expired in 2000. Nita provided excellent leadership to the Commission over the past several years as Chair and I wish to thank her on behalf of all Nova Scotians with disabilities.

Several Commission members saw their term end over the past year and I would like to recognize their contributions. They include:

Community Representatives:

Ted Morrison, Vice-Chair, Glace Bay
Barb Welsford, Lunenburg County
Craig MacKinnon, Halifax
Frank O'Sullivan, Halifax
Scott Hemming, Halifax

Government Representatives:

Aileen Waller-Hebb, Housing and Municipal Affairs
Crystal Taylor, Human Resources

Your commitment and hard work is greatly appreciated.

As this was a transition year in the life of the Commission, with a relatively new membership appointed in 2000, the Commission recognized that while there are many initiatives that we must continue, we felt that it was timely to commit to meeting with the disability community and

hearing directly from persons with disabilities, advocates, parents and other stakeholders on the major issues facing people with disabilities. Thus we hosted a *Town Hall Meeting* in New Glasgow and the information presented at this meeting (included herein) will direct the Agenda of the Commission over the next 12 months.

The Commission has also spent several meetings in review of the Employment Support and Income Assistance legislation and regulations. This new legislation will have an impact on persons with disabilities and the Commission has worked closely and will continue to monitor the affect of the new legislation on the lives of persons with disabilities. Clearly, the development of inclusive employment support services will be an essential component of the new legislation that must be put in place in order that persons with disabilities can access meaningful and community based employment opportunities. The Commission also expressed concerns regarding the level of assistance for persons who can not reasonably be expected to access employment in the near future.

There have been several significant milestones over the past year that will have an impact on the services and thus the lives of citizens with disabilities. The release of the Kendrick Report and the Report of the Special Education Policy Implementation Committee are two examples. The Commission will be monitoring the implementation of the recommendations of these reports.

I would also note that this past year has been very challenging for the staff of the Commission who have moved premises and are currently working in temporary facilities until the offices are completed. I would therefore like to take this opportunity to thank the staff of the Commission for their support and assistance over the past year and wish them well in future endeavors supporting Nova Scotians with disabilities.

Respectfully submitted,

Ralph Ferguson, Chair
Disabled Persons Commission

2. THE DISABLED PERSONS COMMISSION

2.1 Background

The Nova Scotia Disabled Persons Commission was established under the authority of the Disabled Persons Commission Act in 1989. The Act provides a mechanism to ensure a framework exists, whereby Nova Scotians with disabilities can advise policy-makers and program developers on the needs of persons with disabilities. The Act provides a mechanism for persons with disabilities to become policy advisors on issues and concerns which directly affect their lives.

Purpose

The purpose of the Disabled Persons Commission Act is to:

a. provide for the participation of persons with disabilities in the development of government policies and programs which directly relate to or affect persons with disabilities;

b. ensure that the concerns of persons with disabilities will be promoted and considered by the government, especially in matters of policy and where concerns affect several departments of the government;

c. ensure that the concerns of persons with disabilities, are conveyed to the proper department of government and are dealt with in an appropriate, effective and timely manner.

Objectives

The objectives of the Disabled Persons Commission are to:

a. to assist and advise the Coordinating Committee of Ministers on the needs and abilities of persons with disabilities;

b. make the general public aware of the needs and abilities of persons with disabilities;

c. make persons with disabilities and the general public aware of government programs that serve persons with disabilities;

d. make the general public aware of what it can do to facilitate the integration of persons with disabilities into the social and economic mainstream of the community.

2.2 Co-ordinating Committee of Ministers

The Disabled Persons Commission is primarily responsible to the Government of Nova Scotia, through the Coordinating Committee of Ministers. The Chairperson of this Coordinating Committee is the Minister responsible for reporting on disabled persons, the Minister of Community Services, the Honourable Peter Christie. Membership on the Coordinating Committee is comprised of Departments that have a direct stake in provision of services for persons with disabilities.

The following Departments are represented on the Coordinating Committee of Ministers:

Peter Christie, Minister of Community Services
Jamie Muir, Minister of Health
Jane Purves, Minister of Education
Ron Russell, Minister of Transportation and Public Works & Minister of Labour
Angus MacIsaac, Minister of Services Nova Scotia and Municipal Relations

2.3 Commission Members

In 2000-01 a new slate of Commission members were appointed for two year terms which will end in 2002. As well, a new Chair, Mr. Ralph Ferguson, was appointed. Mr. Ferguson was recommended to serve as Chair by the members of the Commission. The following members were appointed:

Community Members:

Ralph Ferguson of Pictou, is a returning member to the Commission. Mr. Ferguson is the chair of Let Abilities Work in Pictou County and is the Commission's representative on the Nova Scotia Building Code Advisory Committee.

William Crawford of Yarmouth, is the president of the Handicapped Organization Promoting Equality (Yarmouth) and is the representative for Nova Scotia's League for Equal Opportunities to the Council of Canadians with Disabilities.

Scott Gillis of Kentville, is a practicing lawyer and chair of the Kings County Partnership Committee for Persons with Disabilities and is a board member of the Multiple Sclerosis Society of Canada/Atlantic Division

Audrey Harmer Guysborough, is a past chair of the Canadian Paraplegics Association (Nova Scotia) and past secretary, Canadian Paraplegics Association (National).

Jane Warren Wolfville, is the chair of the Provincial Survivors Council, Brain Injury Association of Nova Scotia and a member of Feminists for Just and Equal Public Policy.

Brian Tapper of Dartmouth, is a rehabilitation counsellor and a member of TEAM Work Cooperative.

Julianne Acker-Verney Halifax, is a counsellor with the Metro Resource Centre for Independent Living and an active member of the disability community.

Departmental Representatives:

Heather Chandler Diversity Consultant, Nova Scotia Public Service

Commission.

Craig Hinchey	Coordinator of Policy and Evaluation, Department of Community Services.
Karen Ramsland	Program Manager, Community ACCESS-Ability Program, Service Nova Scotia and Municipal Relations.
Shaun Whittleton	Manager of Rehabilitation Programs and Services, Department of Education
Brian Wilbur	Director, Integrated Primary and Population Health Branch, Department of Health

3. DISABILITY IN NOVA SCOTIA

3.1 Definition of Disability

Most members of the general public would probably consider the meaning of the term disability quite obvious. In reality, however, disability is a complex phenomenon, with different meanings for different people. To some, disability simply means some type of medical condition resulting in physical or mental abnormality. To others, disability is characterized by an inability to do things that most other people can do. To still others, it means economic or social disadvantage because of environmental circumstances that can't accommodate physical or mental 'difference'. Each of these popularly understood meanings has some validity. Each by itself, however, fails to capture the full reality of disability.

Since 1981 untangling the complexities of defining disability has been a continuing priority for the World Health Organization. Its two decade old initiative to develop an internationally recognized definition of disability has resulted in the now much refined International Classification of Impairments, Disabilities and Handicaps. It became clear to the International

Committee early on that disability could not be defined adequately except in the context of the underlying impairment and the resulting handicap. Separating and exploring the relationships between these three key components of the disability phenomenon has expanded our understanding of disability and opened doors to creating effective strategies for maximizing the potential of people with disabilities world wide.

Within the International Classification of Impairments, Disabilities and Handicaps:

> Impairment means: an abnormality of bodily structure or organic function due to an underlying disease, trauma or medical condition.
>
> Disability means: functional limitations, or inability or reduced ability to perform a 'normal' range of activities due to impairment.
>
> Handicap means: disadvantages experienced by individuals because of the interaction of impairments and disabilities with the surrounding environment.

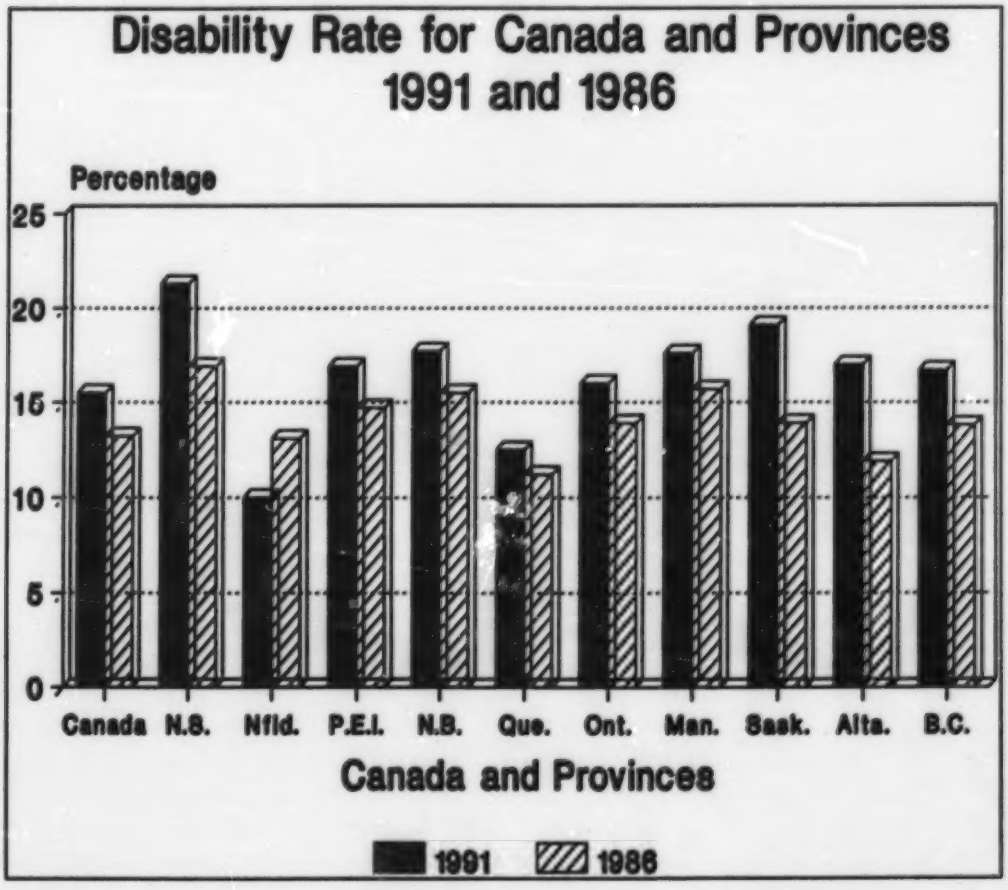
The central notion here is the interaction of impairments and disabilities with the environment. People with impairments do not necessarily have functional limitations or disabilities; and people with disabilities are not necessarily handicapped in their physical and social environments. Let's take, for example, a person whose impairment is serious facial disfigurement as a result of a fire. The disfigurement may have no impact at all on his or her ability to perform 'normal' activities (no disability). The individual may nonetheless experience serious disadvantage (handicap) accessing employment in an employing organization where negative societal attitudes towards disfigurement prevail. By contrast, take the example of someone that has sustained a spinal cord injury in a diving accident and now uses a wheelchair for mobility. This individual clearly has both an impairment and a disability. Nonetheless, in an accessible and socially aware workplace where appropriate accommodations are available, the impairment and disability do not necessarily result in reduced capacity to access and maintain employment; that is, in handicap. Separating the three components of disability, then, and in particular highlighting the important role played by environmental responses to impairments and disabilities, has provided important insight into how we might harness the untapped potential of the disability population and thereby expand the pool of available labour.

3.2 Profile Of Disability In Nova Scotia

A Statistical Profile

According to the most current figures available from the Health and Activities Limitation Survey carried out by Statistics Canada, there were 4,184,685 persons with disabilities in Canada in 1991. This represents 15.5 percent of the Canadian population. The comparable figures for Nova Scotia in 1991 were 189,455 persons, or 21.3 percent of the Nova Scotia population, a significantly higher rate than the Canadian average. In fact, the disability rate for Nova Scotia was higher than any other province in Canada, and almost 6% higher than the

FIGURE 1



national average. In addition, the results of the 1986 Health and Activities Limitation Survey showed similar results with Nova Scotia having a disability rate of 16.9 percent (more than 3.7 percent higher than the 1986 Canadian rate of 13.2 percent (Figure 1)).

The prevalence of disability in Nova Scotia has also been estimated based on questions contained in the National Population Health Survey. In the 1994-95 National Population Health Survey, about 20 percent of adult Canadians and 27 percent of Nova Scotians indicated that their activities were in some way restricted due to a long term physical or mental condition. This indicates that the rate of disability has increased significantly in Nova Scotia since the last Health and Activities

In addition, recently released figures from Statistics Canada indicated that 27.5 percent of the Aboriginal population in Nova Scotia reported having a disability, while a total of 60.5 percent of the Aboriginal population over 55 years of age reported having a disability.

Of those reporting disabilities in Nova Scotia in 1991, 52.6 percent were female (99,685) and 48.0 percent were male (89,770). There were 15,275 children between 0 to 14 years of age with a disability, 108,135 persons between 15 and 64 years of age, and 66,045 persons 65 years of age and over reporting a disability. Table 1 provides the disability population size and percentage by age grouping and gender for Nova Scotia.

A full profile of persons with disabilities is available from the office of the Disabled Persons Commission at no charge.

TABLE 1
DISABILITY RATE AND SIZE BY AGE AND SEX, NOVA SCOTIA 1991

TOTAL POPULATION		
AGE (YEARS)	DISABILITY (%)	POPULATION SIZE
Total Population	100.0	189,455
0 - 14 years	8.1	15,275
15 - 64 years	57.1	108,135
65 - 74 years	19.9	37,745
75 - 84 years	10.2	19,270
85+ years	4.8	9,035

FEMALE POPULATION		
Total Population	100.0	99,685
0 - 14 years	6.7	6,695
15 - 64 years	57.8	57,600
65 - 74 years	18.2	18,190
75 - 84 years	9.9	9,825
85+ years	7.4	7,375

MALE POPULATION		
Total Population	100.0	89,770
0 - 14 years	9.6	8,580
15 - 64 years	56.3	50,530
65 - 74 years	21.8	19,550
75 - 84 years	10.5	9,445
85+ years	----	----

4. DISABILITY EMPLOYMENT TOOL KIT

In 2000-01 the Commission participated and supported the work of Dr. Joan Cummings in the preparation and publication of the Nova Scotia Disability Employment Tool Kit. The Kit, which is available free of charge from the Commission, has three primary purposes:

- to help job seekers with disabilities find employment;
- to help employers find, hire and retain qualified people with disabilities; and
- to help disability employment service providers become more effective in delivering services to both job seekers and potential employers.

BOOK I

Book I is a disability and employment resource manual. It provides background information of general interest. It starts with an explanation of why it is so important at this time to increase job opportunities for Nova Scotians with disabilities. It does on to describe characteristics of the disability population and examines the implications of the changing labour market for job seekers with disabilities. It concludes with links to important web sites where resources related to both disability and employment are available.

BOOK II

Book II is primarily intended for job seekers with disabilities. It guides them inch by inch through every step of the job finding process. It outlines seven major steps, and provides tips and guidelines for each. The steps cover:

- pre-employment planning
- skills assessment
- goal setting and employment planning
- resume preparation
- the actual job search
- the job interview, and
- future career planning

BOOK III

Book III is designed especially for employers. It presents a strong business case for hiring people with disabilities. It dispels myths about disability, identifies barriers to employment and proposes job accommodation strategies. It outlines tips and guidelines for recruiting, interviewing, training and hiring people with disabilities. It describes, as well, several helpful workplace strategies designed to not only support employees with disabilities, but also to improve general worker morale and productivity. It includes important information about human rights and employment equity goals and practices, and describes approaches to effective disability management in the workplace. It concludes with an invitation to employers to work with the disability community towards improving job prospects for Nova Scotians with disabilities. This book is a direct response to questions employers frequently raise about how to expand their available pool of labour and achieve a diversified workforce mirroring the community of which they are a part. *Copies of the Tool Kit are available free of charge from the Disabled Persons Commission.*

5. PUBLIC MEETING - NEW GLASGOW

The Disabled Persons Commission, in conformance to it's mandate to hold meetings throughout Nova Scotia, Held a public meeting in New Glasgow on May 8, 2001, at Summer Street Industries. Summer Street has accessible premises that provided an excellent venue for this public/town hall meeting.

An notice of this meeting was sent to all stakeholders in Northeastern Nova Scotia and as well several weeks prior to the meeting an advertisement was placed in local media newspapers from Guysborough to Truro.

A total of fifty-one individuals and representatives of community stakeholder organizations attended the meeting was chaired by the Honourable Peter Christie, Minister responsible for the Disabled Persons Commission Act and Mr. Ralph Ferguson, Chair of the Disabled Persons Commission. Sign Language Interpreter services were provided by Peter Millman compliments of the Department of Education, Rehabilitation Training Section.

The following individuals made formal presentations to the Commission:

Lisa Smith, Pictou County Early Intervention
Chris Wenzell, Brain Injury Association of Nova Scotia
Judy Hughes, Pictou County Let Abilities Work
Agnes Leblanc, Louisdale, Richmond County, Consumer
Shirley Teasdale, Persons with Disabilities Partnership Society
Fran Nunn, Antigonish, Consumer
Darrell Fiet, Deaf & Hard of Hearing Community
Ron Levy, Central Highlands Association of the Disabled
Joan Boivin, Parents Representing Challenged Residents

During each presentation the Commission engaged in discussion with the presenter. The commission would like to express it's gratitude to all those who attended and participated in the discussion of issues relevant to people with disabilities in Northeastern Nova Scotia.

The issues raised fall generally under the following categories:

- Children with special needs
- Issues of persons with brain injuries
- Access to training and employment
- Mental disabilities
- Access to information
- The deaf community
- Inclusive and accessible transportation

A synopsis of the meeting is provided in Appendix B.

6. DISABILITY WEB LINKS

In 2000-01 staff at the Disabled Persons Commission worked in close collaboration with Human

Resources Development Canada and the Department of Community Services on the national "Disability Links Website.

Developed in consultation with persons with disabilities and service providers, the site contains information on disability related programs, services and initiatives, as well as key contacts. Information on the site is categorized under key topics such as: accessibility, education, employment, health, financial and personal support, housing and residential services, tax programs, and transportation.

Staff at all levels of government and others who serve persons with disabilities and have access to the Internet will also be able to use the site as a quick, convenient, supplementary information resource to assist their clients.

Human Resources Development Canada is managing the site under the direction of the Federal/Provincial/Territorial Ministers Responsible for Social Services. Staff at the Disabled Persons Commission will also be involved in the management of the site through it's designation as the Disability Links Authority for the Province of Nova Scotia.

The site has been specifically developed for persons with disabilities and the site design, layout and technical features reflect the requirements identified by members of the community and internationally accepted guidelines for accessibility.

The Disability Links can be accessed directly at http://www.disabilitylinks.ca or through the Commission website at http://www.gov.ns.ca/disa

7. SPECIAL EDUCATION POLICY IMPLEMENTATION REVIEW

The Commission was represented during the review of the implementation of Nova Scotia's special education policy.

Committee members included parents of children with special needs as well as representatives

from organizations involved with children and youth with disabilities, school boards, the Nova Scotia Teachers Union, universities and government departments involved in providing services to students with special needs.

As a means of background the *Special Education Policy* was introduced in 1996. The main themes of the policy focus on program planning, parental involvement, and a collaborative team approach in the context of inclusive schooling. Implementing the policy has been an ongoing process since 1996 including many parties. At the same time public school education has undergone substantial structural, curriculum and funding changes.

Government's current priority is to develop a multi-year plan for addressing the need for additional resources for children with special needs. As part of that process, it was essential that the progress of policy implementation be reviewed. To that end, Education Minister Jane Purves initiated a provincial review in May, 2000. The Special Education Implementation Review Committee (SEIRC) was established on June 16, 2000.

Mandate

The mandate of the Special Education Implementation Review Committee was to:

- review research and best practices regarding special education programs and services,
- review provincial statistical data on student services,
- receive and review special education implementation reports from school boards,
- review other recent reports and surveys on special education in Nova Scotia including: *"Resistance and Acceptance: Educator Attitudes to Inclusion of Students with Disabilities"*, Bunch et al, 1997; *"Educators Perceptions of the IPP Process"*, NSTU, 1998; *"Report to the Education Committee of the NSSBA from the Ad Hoc Committee on Inclusion"*, NSSBA, 1999; *"Tracking Our Progress"*, Department of Education, 2000,
- review recent special education reviews in other provinces,
- report on the current status of the implementation of the policy,
- identify the challenges to the provision of quality special education programs and services,
- recommend options to overcome the barriers and ensure quality program and services are delivered in the most efficient way possible.

The work of the Committee is completed and the Disabled Persons Commission endorses the recommendations of this report. Copies of the Report are available from the Department of Education.

8. INCLUSIVE TRANSPORTATION INITIATIVE

The Commission continued to participate on the Inclusive Transportation Steering Committee that oversaw three Inclusive Transportation Pilot Projects in Antigonish-Guysborough, Colchester and Yarmouth. In addition this Committee oversees the Accessible Transportation assistance Program that provides financial assistance to organizations that are purchasing accessible vehicles for inclusive community transportation services.

With the ending of the pilot projects the Commission was extremely pleased with the announced "Community Transportation Assistance Program".

The Community Transportation Assistance Program (CTAP) will invest $500,000 a year in inclusive transportation services in rural and semi-rural Nova Scotia.

Under the Community Transportation Assistance Program, individuals, community volunteer organizations and local businesses will work together to develop lasting, viable transportation services for people who cannot use public transit. Ten per cent of CTAP funding ($50,000) is earmarked for a component called the Accessible Transportation Assistance Program, which will help service providers buy accessible vehicles or make existing vehicles accessible.

For more information on the program you can contact Service Nova Scotia and Municipal Relations directly or review the program at:
http://www.gov.ns.ca/snsmr/muns/infr/ctap/community_trans_assist.stm

You may also access this site through the Commission's Website http://www.gov.ns.ca/disa

9. NOVA SCOTIA ACCESS AWARENESS WEEK

The Disabled Persons Commission participated again in the 2001 Nova Scotia Access Awareness Week activities. The major role played by the Commission was again around Provincial activities of the week. This year the theme was *"Full Citizenship For All"*.

9.1 Proclamation Ceremony

This year a proclamation ceremony was held at the Nova Scotia House of Assembly where Premier John Hamm and the Honourable Peter Christie, Minister Responsible for the Disabled Persons Commission, signed and proclaimed Nova Scotia Access Awareness Week.

A highlight of the ceremony was the announcement of this year's Access Awareness Week Poster contest. The contest invited Grade 7 students in Nova Scotia to develop a poster based on the theme *"Full Citizenship For All"*. The winner was Ms. Kendall Rolfe, a grade 7 student at Springhill Junior High. A copy of the winning poster is provided in Appendix B. The Board of Directors of Access Awareness Week - Nova Scotia will develop a poster that will be used in future years based on Ms. Rolfe's design.

9.2 Citizenship Forum

Again this year, the Disabled Persons Commission, in collaboration with Partnership for Access Awareness - Nova Scotia, held a "Citizenship Forum". The purpose of the Forum was to provide an opportunity for the disability community to meet and discuss issues of importance to the achievement of "Full Citizenship For All".

This year the topics included:

Full Citizenship Through Inclusive Transportation

This session provided an opportunity for the Inclusive Transportation Pilot Project Initiative findings to be presented to the community: the successes of the initiative, the issues being faced and where it will go in the future. In particular, the Forum provided an opportunity for the community to receive an overview of the Community Transportation Assistance Program that

has resulted from the work of the Pilot Projects.

Full Citizenship Through Equal Access to Recreation Opportunities

In keeping with the original themes of Access Awareness Week the Citizenship Forum dealt with the issue of equal access to recreation opportunities for people with disabilities. The session was facilitated by Recreation Nova Scotia and readers are invited to review Recreation Nova Scotia's Website at: http://www.recreationns.ns.ca/program/include.htm or the site can be accessed through the Commission's website at http://www.gov.ns.ca/disa

9.3 The Mel Hebb Hour Glass Action Awards

The Commission, as part of it's mandate to advise the Coordinating Committee of Ministers on *"what community in the Province has done the most in any year to improve awareness of accessibility of persons with disabilities"* has supported the work of the Partnership for Access Awareness Hour Glass Action Awards Committee.

Each year during Nova Scotia Access Awareness Week, the efforts of individuals, organizations, and businesses that have made exemplary accommodations to their environment and/or operations in order to be more accessible to the public are recognized. The Award has been renamed in memory of Mel Hebb, who passed away October 3, 1999. Mel provided leadership and inspiration as Chairperson of the Awards Committee, as well as being a volunteer and friend of the Committee and Board of Directors of the Partnership for Access Awareness - Nova Scotia.

This year's award winners were:

StonehAme Chalets, Fitzpatrick Mountain: Owners Donald and Sharon Gunn were recognized for their physically accessible chalets and lodge in the mountains of Pictou County. The nine physically accessible chalets and a lodge with five private guestrooms are ideal for conferences, meetings, retreats or workshops.

Keith MacDonald, Outstanding Individual Award: Keith MacDonald was recognized for his dedication as a volunteer of Tetra Society of Metro Halifax. Tetra recruits skilled volunteer

engineers and technicians to create assistive devices for people with disabilities. This unique program was developed in response to difficulties that people with disabilities experience in their search for greater independence and integration within their communities.

10. NOVA SCOTIA NEUROTRAUMA INITIATIVE

The Nova Scotia Neurotrauma Society was created as a partnership interested in promoting the fields of neurotrauma research, prevention and rehabilitation. A network of provincial neurotrauma funds was promoted by the Rick Hansen Man In Motion Foundation, as part of the tenth year anniversary celebration at the end of the Man In Motion World Tour.

Staff of the Disabled Persons Commission provide administrative and research support to the work of the Nova Scotia Neurotrauma Society.

During 2000, a total of five grants were awarded to researchers and community organizations to improve the quality of life for persons who have sustained a neurotrauma injury.

Rehabilitation:

1. "Behavioural based Programming for Transitional Living Facility (Aiseirigh House)"
Brain Injury Association of Nova Scotia

Aiseirigh House has been designed by the Brain Injury Association of Nova Scotia(BIANS) to serve two needs. The first is to demonstrate that many moderately-to-severely brain injured residents can become more independent and be successfully integrated into the community. Second, the pilot project has been designed to demonstrate through evaluation of specific outcome measures, that this program represents a needed element of care in the Province's continuum of care. Thus, the project is designed to meet some of the needs of the brain injured community in Nova Scotia

Prevention:

The Nova Scotia Neurotrauma Society awarded one grant in 1999-2000 , to aid prevention. It

was awarded to the Spinal Cord Injury Prevention Association of NS for their project titled *"Bicycle Helmets for Children of Families with Low Income"*. The focus of this project was on the prevention of Brain and Spinal Cord Injuries through the provision of 500 helmets for children whose families are not in a position to afford the obligatory requirements of the bicycle helmet legislation.

Research

Three projects were awarded in the area of "Research" in 2000.

1. *"Combined Effects of Exercise Training and Creatine Supplementation on Skeletal Muscle After Spinal Cord Injury"* Acadia University: Rene Murphy

2. *"Innovative Electrophysiological Assessment Methods in Traumatic Brain Injury"* Dalhousie University: John Connolly

3. *"Mechanisms of Recovery After Traumatic Brain Injury"* Dalhousie University: Gary Allen

11. OTHER ISSUES AND INITIATIVES

11.1 Human Rights Commission Organizational Review

Members of the Disabled Persons Commission were involved in discussions with the Nova Scotia Human Rights Commission in regards to Phase 1 of it's Organizational Review. In particular the Commission reviewed and made comment on the document "Moving Forward With Human Rights In Nova Scotia".

A key consideration and comment of members of the Disabled Persons Commission is that persons with disabilities must have a distinct voice that can promote issues of disability within the Provincial Government and with the general public. As well, Commission identified that

there are areas of cooperation whereby the resources of both Commission's could be used to foster positive change on behalf of persons with disabilities in Nova Scotia.

11.2 The Kendrick Report

The Commission was involved in the work of Dr. Michael Kendrick as he prepared and released his report *"An Evaluation of the Nova Scotia Community Based Options Community Residential Service System"*, an independent review of Nova Scotia's Community Based Options which calls for continuing efforts to better serve people with mental or physical disabilities. Reader's may view the report at: http://www.gov.ns.ca/coms/review.htm or through the Commission's website at: http://www.gov.ns.ca/disa.

The Commission's involvement included working with a community committee to organize a one day work shop with Dr. Michael Kendrick. Dr. Kendrick used the findings of this workshop in the development of the report's recommendations. *A synopsis of the finding of this work shop are included in Appendix C.*

The Commission, upon review of Dr. Kendrick's report, endorsed the direction of the report's recommendations.

11.3 Tracey Latimer

Given the public debate over the Supreme court of Canada's ruling concerning the Tracey Latimer Case the Commission reviewed it's 1998 position paper concerning the issue and continues to endorse it's findings.
In summary the position paper states:

> *"The Nova Scotia Disabled Persons Commission, through it's mandate to advise Government and the general public on the needs and abilities of persons with disabilities has, through discussion and reflection, prepared a document that addresses some the central issues of this tragedy. The Commission believes that through sharing it's reflections, future tragedies can be prevented."*

In conducting it's deliberations and in review of public policy issues, the Disabled Persons Commission has identified several key principles that it uses to assess these policies from a disability perspective. These principles are intended to reflect the core values of persons with disabilities and are used to direct the assessment of policies and programs and in discussion of issues such as the Tracey Latimer case. These principles are:

Equal Citizenship
Equality of Opportunity
Dignity
Full Inclusion and Integration
Consumer Participation

The Disabled Persons Commission believes that the public debate and concerns raised over the Latimer Case and other related legal cases, raises issues of particular significance to persons with disabilities. Medical research and modern technology have imposed significant ethical and moral issues upon our society. Decisions of life and death, quality of life, cost and benefit of support services, and a wide range of issues related to gene therapy and manipulation have imposed great ethical dilemmas upon the health care professions, legislators, and the general public.

Given the complexity of the Latimer Case and the many related cases, the Disabled Persons Commission wishes to ensure that the principles of Equal Citizenship, Equality of Opportunity, Dignity, Full Inclusion and Integration, and Consumer Participation remain central to the manner in which decisions are made concerning these modern ethical questions. As well, a forum for Government and professional organizations to consider, debate and reflect upon these complex and ethical considerations with the disability community, is critical. The ethical considerations of research, program planning and resource allocation must include the disability community.

While the Tracey Latimer tragedy occurred in Saskatchewan, it could happen in Nova Scotia. We must do all in our power to prevent a similar tragedy occurring here. In recognition of the impact of the Latimer tragedy and to reduce the potential for similar tragedies occurring in Nova Scotia and in support of it's principles, the Disabled Persons Commission recommends:

Recommendations

1. Families that provide care for children with disabilities should be given the necessary supports to ensure that the family unit is a positive environment.

2. Intrinsic to family support is a full continuum of respite services for families who provide care for family members.

3. Palliative care is an essential component of Home Care services and must continue to receive high priority for full implementation.

4. Pain management should be a priority of not only a palliative care program, but also seen as a priority in regards to the amelioration of disability related pain and should be delivered in a manner that is reasonably accessible to all Nova Scotians.

11.4 Access to Real Government Property

The Commission continues to work on developing pragmatic and thoughtful policy recommendations for Government in regards to access to Government leased and owned real property. Twenty-two Government office spaces (leased and owned) have been audited using the audit tool developed through the work on this initiative.
As an update, the Commission believes that a final report and recommendations will be finalized in early 2001-02.

11.5 Employer Recognition/team Work Cooperative Ltd.

The Disabled Persons Commission continues to work closely with Team Work Cooperative Ltd. and the Collaborative Community Partnerships across Nova Scotia. In February the Commission, in partnership with Team Work Cooperative, and with funding support from Partnership for Access Awareness - Nova Scotia, hosted an employer appreciation luncheon and a formal launching of the Disability Employment Tool Kit.

The recognized employers, Atlantic Superstores, Staples Inc., Sheraton Halifax Hotel and Convergys Customer Management Canada Inc., have participated in a Skills Training

Partnership (STP) Initiative.

The program is sponsored by TEAM Work Co-operative in partnership with the Canadian Council on Rehabilitation and Work (CCRW), and Human Resources Development Canada (HRDC). This initiative has provided 48 jobs for individuals with disabilities since the program began in 1999.

The Disabled Persons Commission is proud of it's partnerships with such organizations as Team Work Cooperative Ltd. and the collaborative Community Partnerships.

11.6 Information And Referral

Staff of the Disabled Persons Commission assist individuals with disabilities and the general public to understand and access programs and services that are designed to assist individuals with disabilities. The Commission's Toll Free telephone lines are as follow: 1-800-565-8280 *and* TTY: 1-877-996-9954.

In 2000-01 this work has been supplemented by the Disability Web Links as mentioned earlier in this document. The Commission's Web Address is http://www.gov.ns.ca/disa and the Disability Web Links site can be accessed through the Commission's site or directly at http://www.disabilityweblinks.ca

APPENDIX A

APPENDIX A

DISABLED PERSONS COMMISSION
PUBLIC CONSULTATION
HELD
MAY 8TH, 2001
AT
SUMMER STREET INDUSTRIES
NEW GLASGOW, NS

The Disabled Persons Commission, in conformance with it's mandate to hold meetings throughout Nova Scotia, held a public meeting in New Glasgow on May 8, 2001, at the Summer Street Industries location. Summer Street has accessible premises that provided an excellent venue for this public/town hall meeting.

An notice of this meeting was sent to all stakeholders in Northeastern Nova Scotia and as well several weeks prior to the meeting an advertisement was placed in local media newspapers from Guysborough to Truro.

A total of fifty-one individuals and representatives of community stakeholder organizations attended. The meeting was opened by the Honourable Peter Christie, Minister responsible for the Disabled Persons Commission Act and chaired by Mr. Ralph Ferguson of the Disabled Persons Commission. Sign Language Interpreter services were provided by Peter Millman compliments of the Department of Education, Rehabilitation Training Section.

The following individuals made formal presentations to the Commission:

Lisa Smith, Pictou County Early Intervention
Chris Wenzell, Brain Injury Association of Nova Scotia
Judy Hughes, Pictou County Let Abilities Work
Agnes LeBlanc, Consumer, Louisdale
Shirley Teasdale, Persons with Disabilities Partnership Society
Fran Nunn, Consumer, Antigonish
Darrell Fiet, Deaf & Hard of Hearing Community
Ron Levy, Central Highlands Association of the Disabled
Joan Boivin, Parents Representing Challenged Residents

During each presentation the Commission engaged in discussion with the presenter. The Commission would like to express it's gratitude to all those who attended and participated in the discussion of issues relevant to people with disabilities in Northeastern Nova Scotia.

The issues raised fall generally under the following categories:

A. Children with Special Needs
B. Issues of Persons with Brain Injuries
C. Access to Training and Employment
D. Mental Disabilities
E. Access to Information
F. the Deaf Community
G. Inclusive and Accessible Transportation

A. Children With Special Needs

The first speaker highlighted the importance of the early years when there was only one day care in the County.

Primary concern: Lack of accessible, quality daycare and preschool options for children with disabilities.

The importance of the pre-school years was highlighted:

> *"children who take part in programs in loving, stimulating social and educational environments are more likely to adjust well to school and fulfill their potential. This is as true for children with disabilities as for those without."*

It was further noted that transition into school is a significant challenge for parents of children with special needs.

1. Day Care Inaccessible Due to Financial or Placement Reasons.

Presently there is only one daycare in the County, in the New Glasgow area, with subsidized

positions. It is also the only daycare with a special needs differential. Subsidized spots and placements for children with special needs are limited.

Physical access to day care facilities is an issue. It was noted that there is currently a program "Community Access-Ability Initiative" that could provide up to $10,000 to community organizations to assist with accessibility retro-fits.

Transportation, particularly accessible transportation, is a barrier to attendance at day care. It was further noted that the recently announced "Community Transportation Assistance Program" will have a positive affect on the availability of accessibility transportation in Pictou County.

It was indicated that there is currently a waiting list for children with special needs for spaces in an appropriate day care setting.

2. Pediatric Occupational Therapy Needs

Children served by the Pictou County Early Intervention Society could benefit from the input of a pediatric occupational therapist, who would specialize in adaptive seating, orthotics, fine motor skills, adaptations needed for learning independence in self-help skills, special feeding and sensory-motor Integration.

In Pictou County you must access these services from the IWK-Grace in Halifax. Many children have never been assessed by a proper occupational therapist.

3. Access to Inclusive Recreation Opportunities

A third issue raised was lack of access to truly accessible recreation opportunities for children with special needs.

> *"most recreation programs and facilities in this county are simply not equipped to include children with special needs." It was noted that work is*
>
> *currently underway to build a state of the art accessible playground and that Recreation Nova Scotia has instituted an accessibility initiative with the Active Living Alliance. Information can be obtained through the Commission's website (www.gov.ns.ca/disa).*

Other issues raised concerning children with disabilities included:

- High cost of equipment for children with Special Needs.
- Full inclusion policies: School boards tend to save money by allowing salaries to commence only during school hours so there is no opportunity for assistance during playground times.
- Recreational Activities: More modifications for programs for children in wheelchairs and more modifications to playgrounds and school grounds needed.
- Access to information when a child is born with a disability there should be a directory of services for parents. The average parent does not have strong advocacy skills.
- There should be strong government involvement for respite services. Parents need a break.

  "My son is in a group home that is not accessible: it is not designed to be wheelchair accessible."
- Remove the freeze on group homes and small options.

B. Issues of Persons With Brain Injuries

"Brain injury is sometimes depicted as a nervous disease or lack of intellectual capacity, neither of which is true. We have lost the ability to use our brain quickly and efficiently our intelligence is not lost."

In many instances a nervous breakdown or suicide is the result of a brain injury as a result of a misunderstanding on the part of professionals, para-professionals or the general public (family and friends).

Recommendation:

Brain injury should be given a separate classification instead of being classified as a mental disability by the Department of Community Services.

The notion of a brain injury as a disability would heighten public awareness and understanding and provide a venue for targeting additional resources in this area. It was noted that research on ways to improve outcomes following a brain injury is definitely needed.

There is a need for more public awareness regarding injury prevention: i.e., bicycle helmets, seat belts, etc.

It was further noted that the term "seat belt" would be better described as a "safety belt" to indicate the true purpose of "buckling up".

It was also noted that survivors of traumatic brain injury often have trouble remembering, concentrating, making decisions and controlling impulses.

A traumatic brain injury can alter dramatically education and career goals and have a devastating affect on relationships with family and friends.

A major issue faced by persons with traumatic brain injury is that the disability is not readily apparent which leads to misunderstanding and the reason brain injury is known as the "invisible epidemic".

In conclusion, the presentation asked for Commission support in defining brain injury as a distinct and separate category of disability.

C. Access to Training And Employment

In reporting on Pictou County Let Abilities Work , it was stated *"We are working wonders thanks to dedicated and committed individual and volunteers."*

Accessibility Committee:

- Accessibility is a matter of economic policy.
- A survey of the County of accessible businesses has been completed.

The Deaf Community:

- Needs Assessment: Full Time Interpreter
- Getting Interpreters out of Halifax has been extremely difficult

Mental Health Consumers:

- We are not doing a very good job.
- We need new ideas and new models of service delivery for mental health consumers.

Youth:

- School to Work transitions is a key area.

Other

- Inclusion and Equity Committee in Pictou County has been successful.
- Success in Pictou County comes from many thousands of hours of volunteer work over the past two decades.
- The one hundred and seventy clients of Let Abilities Work have an economic impact of $600,000 value in the Pictou County economy.
- Seamless approach is needed: Community Services/HRDC have their own rules and terms and conditions: consumers don't care what the mandate is; they just want to get to work.
- A single focus, seamless approach, on programming is needed
- Access to technology: most people don't have IT skills or access to the necessary equipment
- We need Supported infrastructure on pre-employment skills
- Job supports are needed once on the job: mentors, etc.
- Infrastructure around retention: help retain employment
- More opportunities for mentoring
- Literacy continues to be a major issue.

D. Issues of People With Mental Disabilities

Persons with a mental disability are in a "Catch 22". You need to maintain your Pharmacare benefits.

Rapid Reinstatement is not working: three months is not enough transition time / re-evaluation.

"How do you sustain employment when you run into crisis?"

"I believe that HRDC has placed full responsibility for employment on the backs of the community through these partnership committees."

It is essential to get more funding partners in the Partnership Committee model.

The Mandate is strictly employment for HRDC.

The partnerships are misleading the disability community in regards to the services they can provide to the disability community. They are focusing only on those who are "employable".

The level of income assistance for those who cannot gain full time employment is insufficient.

There is a glaring need for a national pharmacare program, particularly for people with disabilities.

"Has society given up on caring for the mentally disabled?"

"We are mental health consumers but what do we consume?"

There is definitely a need for a national pharmacare program.

Persons must have the freedom to take risks.

Small options for the mentally ill are desperately needed.

E. Access to Information

There are good services out there (Ronald McDonald House, In Home Support) but a typical parent does not know about them.

Why doesn't the Commission have a newsletter?

We need to do some asset mapping and coordinate programs that currently exist. The services are fine but if I don't know about them ...

A discussion ensued on the "disability link" website that contains information on programs and services for persons with disabilities. This database is accessible at www.disabilityweblinks.ca or through the Commission's website at www.gov.ns.ca/disa

It was further noted that the Commission has a directory of programs and services that is available upon request.

F. The Deaf Community in Pictou County

Certified and qualified interpreters are not available for such things as doctors appointments. There should be some flexibility in the Provincial Policy.

Availability of emergency interpreting services is problematic in Pictou.

Accessible parking spaces should be accessible to the Deaf community.

A Needs assessment in Inverness County met with local Deaf community, and parking was an issue.

G. Inclusive and Accessible Transportation

- Affordable accessible public transportation is a basic need
- Transportation is the only link to participation in the community.

Chad:

- 110,000 km per year
- 19,000 passengers
- This is double 1996 statistics.

- Volunteers up to 100 hours per week (savings of $50,000 per year)

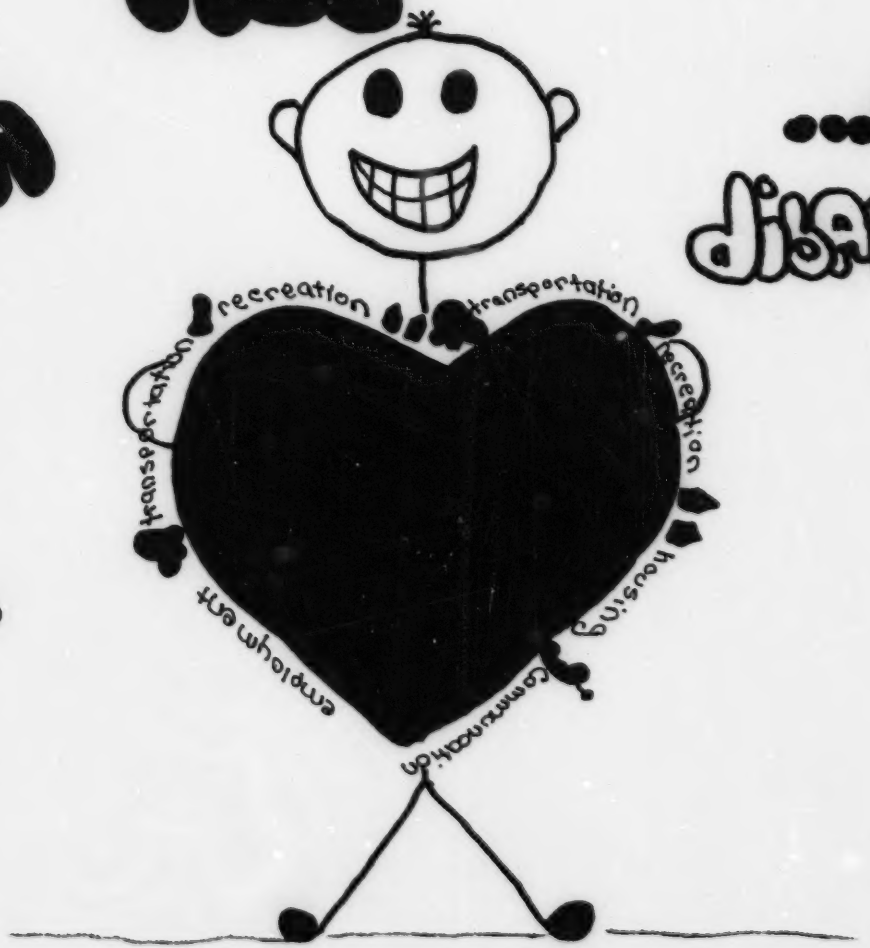
- Sources of funding municipal units, services clubs and the fare box
- The community Transportation Assistance Program (CTAP) will make a big difference.
- All three levels of government must be involved.
- The Commission should lobby for funding from the Federal Government

All representatives were thanked for their participation and it was indicated that the proceedings would form the basis of the Commission establishing it's agenda for the upcoming year.

CMacd/bc
June, 2001

APPENDIX B

"Full Citizenship for All"



...with disabilities.

Have a heart, help them...

Kendall Rabb

APPENDIX C

APPENDIX C

COMMUNITY BASED OPTIONS REVIEW
WORKSHOP
WITH
DR. MICHAEL KENDRICK
MONDAY, JULY 17, 2000

BACKGROUND

Dr. Michael Kendrick has been contracted by the Province of Nova Scotia to review and report on the Community Based Options Residential System.

As a means of providing input to the process as well as providing Dr. Kendrick with an opportunity to discuss issues and concerns with community stakeholders a one day workshop was held July 17, 2000. Participants came from residential service providers, parent/advocacy organizations and consumers. A full list of participants is attached as Appendix A.

PROCESS

The Workshop was organized into three key parts:

Part A: Presentation by Dr. Kendrick.

Part B: Group Discussion: What Major Questions Must be Answered?

Part C: Plenary Discussion

The following is a brief synopsis of the discussions.

PART A: PRESENTATION OF DR. MICHAEL KENDRICK

Terms Of Reference

Dr. Kendrick spoke to the terms of reference of the review:

Terms of Reference are broad: basically to evaluate the community based options residential

system.

This means answering the following questions:

- What is the current state of best practice?
- How are we doing?
- How can we improve?

Dr. Kendrick indicated the broad outlines of his report is nearing completion. It is Dr. Kendrick's understanding that his report will be shared in its entirety with the public.

Purpose of Workshop

Dr. Kendrick reviewed his understanding of the goals of the Workshop:

- To gather input: concerns and issues
- To talk about the broad concerns of the review: not the details or specific recommendations.

Some Themes

The report will deal with the *system* not particular homes.

It is the *system* that has created the residential services that exist today.

Two key evaluation questions are:

What good did it do? *or*

What have been the effects of the system and are these effects desirable?

In every jurisdiction there is a *state of the art* culture. The 1950's had a way of doing things and there is a way of doing things today. There is *conventional* practice.

Nova Scotia is not dissimilar from other jurisdictions in many respects

There is a "formal" and an "informal" system.
The best things usually happen "informally".
Many things are done in every system "despite" the system and this is not unique to Nova

Scotia.

It is important to note that criticism of the formal system is not meant to be critical of the people working in this formal system. This is particularly true given the many years this particular formal system has been in place in NS

It is notable that the Nova Scotia formal system has remained largely unchanged during the most significant period of change in the manner in which services for persons with disabilities are viewed.

Decision Making

Dr. Kendrick emphasized his report is advisory and that it will be up to the Province of Nova Scotia to review his findings and decide whether or not to implement any (or all) of his recommendations.

In his discussions with hundreds of stakeholders, he identified there was a widespread and significant issue whether the motives of the governmental bureaucracy are to be trusted in regards to the review. There is considerable concern the Province will not do the "right thing" for the right reasons. Dr Kendrick expressed concern that these perceptions, correct or incorrect, indicate a deep rupture between the community and the bureaucracy and this is ultimately not very helpful if progress is to be made. This lack of confidence must be repaired in the interest of establishing public trust.

What is practical versus what is possible is based on different factors in different jurisdictions. It may not always be immediately possible for any jurisdiction to initiate the advances of another if that same jurisdiction has not done its own preparations for progress. There may be a necessary learning period.

You cannot take something from one jurisdiction and immediately implement successfully. The pre-conditions are generally different.

"It may take some time"

The interpretation or operationalization of the *principles* of a system may define exactly what that system turns out to be not the expressed principles in themselves.
Leadership and vision are the key ingredients in forward progress. It is quite possible that these

need to be renewed periodically if stagnation is to be avoided.

Successful implementation of renewal will take innovation and the pushing past of the boundaries of established systems.

Leadership implies *taking leadership* and not sitting back and expecting someone else to take all the responsibility for forward progress.

Leadership is not only held in *formal roles of authority* but usually needs to complemented by the nurturing of informal leaders

Leadership is more fundamentally a trait of individuals rather than a capacity of a system though many systems recognize their responsibility to provide the conditions that enable leadership to emerge.

The Assumption of No New Money

Dr. Kendrick indicated his report and recommendations will be written with the assumption of *no new money.* This is not meant to suggest new funds could not play a role but rather that the key question will be *how to spend the money already in the system more wisely.*

If you change how you are spending the *money* today you will change the system.

Some of the *better funded* systems in the world are operating under outdated practice.

The level of spending does not relate to the level of thinking. Hence, good thinking about better practice is more crucial in the long run as it sets the stage for the better use of available resources.

What Is Better Practice?

The *residentiallizing* of people's needs i.e., interpreting what people need based on presently available residential service models, is not good practice as there is a danger of fitting people to models rather than creating models that arise from people's needs.

A good service is the service that is most relevant to what people actually need. Hence, a residential service model is more likely to be sound if it is highly tied to the very specific needs

of individuals, rather than simply a copy of standardized service models.

Better services will not try to get people into fixed service models or systems but rather be organized to get people more precisely what they need.

The *personalization* of service supports on an individual by individual basis is key.

Though it may surprise some people it is possible people could actually have a place to live but not have much of a *life*.

Residential service supports should be secondary to achieving life goals or in other words;

Beds should not be confused with *lives* i.e., lifestyle support should be the focus instead of simply obtaining residential service placement.

Personalization of supports should be the focus and there should be:

Avoidance of fixed or formula of service or support models (conventional standardized models).

The current system under the current act is focused on facilities. Hence, there would be merit in shifting from a facility based system to one more closely attuned to the possibility of more varied individualized supports: The Homes for Special Care Act could become an *Act for Personal Community Supports for Nova Scotians* which supports the individual and their lifestyle.

There is a need to emphasize personal needs and decision making when it comes to service design. This would mean quite an expanded role for consumers and families than either they or the authorities are currently familiar with.

In effect this would mean a move to a *bottom up* model.

There needs to be a distinction between freedom vs. licence. People must have comparable freedoms to their fellow citizens but this does not mean getting everything you want. As such, any expanded consumer or family involvement would need to be predicated on the assumption of strengthened responsibilities to accompany strengthened powers in any more flexible system that emerges.

It is crucially important we get better at designing services *with people* rather than simply placing people into vacancies.

People with disabilities are among the most vulnerable people in the world. Their interest could be damaged by people who don't know better - even if they mean well. It is crucial to equalize the playing field by recognizing their *relative endangerment.* Aggressive, principled independent advocacy is critical as this acts to balance the many disadvantages that come with being relatively powerless vis a vis so many people in society and services.

Without individual advocacy people with disabilities are at risk.

Many people with disabilities find the *strain* of personal advocacy very draining as do their families and are demoralized by any system that can only be changed by aggressive advocacy. Hence the need for service arrangements that are more collaborative rather than oppositional.

"Community Services"

Best practice is achieved when people are properly served in the community and can take advantage of all that community life offers.

Substantial numbers of people in residential services are still either quasi-segregated or remain in institutions and mini-institutions long after such arrangements have changed in mainstream thinking and practice. There is no justification for this at the level of what is now practical in the field.

A system that perpetuates weak ties with the community makes people with disabilities more vulnerable.

There is ongoing tension around the question of whether we have a largely custodial system or a system in which people develop as individual. *cared for* does not mean *having a meaningful life.*

Maximal Flexibility at the Level of Practice

In most jurisdictions people must fit to a system rather than be able to practically create the system of supports that would best match their lifestyle.

When living within the context of a group you tend to be pressured to do what is good for the group and compromise to an extent what is good for you.

The more flexibility you can give individuals to create their own lifestyle the more you can account for the different needs of people.

The best services enable flexibility of service design and practice and allow this flexibility to remain substantially under the control of the person being affected and not their *keepers.*

A key starting point in achieving this is developing authentic partnerships with people beginning with the first stages of the design of services.

People and their families must be authentic partners not simply service recipients and thus the *co* or joint design of service is the key piece of getting this partnership starting within the right ethic.

Better Systems Emphasize Four Elements

1. Emphasis on VALUES

If people are going to be treated well the system must have strong VALUES that uphold the deep human needs of people to be seen and treated as being valued.

The system must take such VALUES *seriously.* Values must correspond to how people really are treated. Values that become internalized by the person emerge as a set of ethics guiding behaviour more than just a matter of well intentioned verbalization.

The stated values ought not to be different than the lived values or deceptive mythologies will arise that serve to cover up such contradictions and thereby obscure what is really underway.

Values are open-ended until they are concretized into some manner of definition; their interpretation will define the system. This is because the actual living out of a value always reveals a specific understanding of it. For instance, the value is often stated that people should be involved in shaping the service they get yet this is often interpreted in practice to mean simply having a formal individual planning session once a year. Clearly, the same value could have been interpreted more broadly to mean involvement in how services operate for that individual every day of the year.

The values question is a constant evolution as is the interpretation of such values. When values are frozen into sterile mission statements the dynamism of continuous application and interpretation of values is lost.

In good systems, values are recognized as something that must be talked about a lot, perhaps incessantly. Such a dialogue is meaningless if people other than the managerial classes are excluded from participation. Hence the healthier systems will be ones with intense public discussions on all matters that touch on values and the well-being of people. Values rest at the core of how people are seen and treated and are intrinsic to the well-being of people .How these get interpreted and operationalized in daily practice is a "values" question and ought to be consciously linked to practice.

2. Emphasis on LEADERSHIP

There is never enough sound leadership. The exercise of positive leadership is crucial to forward progress. Similarly, the presence of insufficient, outdated or inadequate leadership is extremely costly to forward progress. Leadership is ultimately embedded in particular persons and the alliances they make with other leaders. Where these persons are absent or rendered unable to develop, the price to forward progress will be measurable.

Consequently, the recruitment, enrichment and renewal or revitalization of leadership is critical

People and systems go in cycles (highs and lows)

Leadership development and mobilization will be necessary to maintain forward progress. Leaving its cultivation to chance constitutes poor management and strategy

The presence of fundamental challenge of and in the system is leadership in practice and thus the absence of innovation is usually a sign of an absence of effective leadership. It is also true that the failure to construct adequate corrective responses to valid challenges to the merit of the system is a sign of poor leadership.

3. Emphasis on Human Judgement as the Cornerstone of Both Service Quality and Personal Security

The safety of vulnerable people in support arrangements is not ultimately a function of bureaucratic standards or other formal paperwork or procedural systems but rather resides more

fundamentally in the good judgement of people in daily practice.

There is no evidence formal prescriptive systems can replace the need for and emphasis on judgement since it is really people that must ultimately protect and advance peoples' circumstances. Manuals, rules, *systems*, procedures etc. may actually help obscure what it is that keeps people safe since they create the illusion of protection via the compliance with paperwork.

When you entrust the lives of vulnerable people to any such abstract technocratic system you must ensure there is good judgement as a core component (and exercised in) of that system.

People must normally be helped to some degree with good judgement. Everyone has *soft spots* in judgement some of the time and good judgement is linked to positive values and wise interpretation. This is an ongoing problem of service practice and is rarely impacted by the creation of minimal standards training and certifications since so much of what is important actually resides with what happens in daily practice.

4. Emphasis on Establishing Innovation Oriented Practice and Environment

Unless you are able to innovate you cannot respond flexibly to the needs of individuals

A system that is demonstrably innovative must have innovation as a common place activity and this means creating an atmosphere that encourages people to imagine better and to follow this up with deliberate experiments with new possibilities. While innovation is something that can happen by serendipity it is unwise to count on this *accidental* strategy. It is better to deliberately maximize the emergence of innovation by setting goals and challenges for this purpose, welcoming and rewarding innovation, creating mechanisms for experimenting and, most importantly, strengthening the presence of innovation minded people.

Some Closing Statements on Implications

It is time to re-visit the underlying thinking epitomized in the largely facility oriented Homes for Special Care Act. Unless there is a desire to continue to produce a fixation on service facilities rather than on people's lives and the creation of *real homes* then the balance must shift to people and their aspirations rather than a set of *fixed* or standardized program models.

A classification system based on a limited menu facilities system will be contrary to personalized

flexible supports. A priority/eligibility system would be more appropriate

Over time there would be a need to transform the current fixed model system into a system that could more routinely and competently produce a wide variety of personalized community supports. This is a difficult task, particularly in the beginning, and will proceed more rapidly and with quality if accompanied with support to help people shift their thinking, habits, practices and even attitudes. As a consequence, the prelude to the implementation of such a challenge would need to see carefully selected efforts at long term *people building* strategies to strengthen their capacity to rise to this challenge. Perhaps the most crucial of these would be the leadership and nurturing innovation efforts alluded to thus far but it would eventually need the "judgement strengthening" efforts which have also been mentioned. The latter could begin around high-risk individuals immediately.

Since the actual supports people receive are more central to the larger equation of people's lives why licence facilities rather than the people responsible for supporting the facilities? As such, the prospect of a re-thinking of the focus of licensing needs to be considered.

The people served and their friends, families and advocates need more explicit authority in negotiations on service design and implementation if they are to properly balance the control, authority and power that has slipped into the hands of managers, staff and professionals. These measures of delegated authority would include the power to imagine better, the power to refuse service or practices they believed to be inadequate, the ability to propose and negotiate counter proposals, a manner of strong ongoing influence on resources and their use and significant roles in safeguarding people and innovating.

A single method *bureaucratic* monitoring model still leaves vulnerable people substantially at risk. A broad based multi-faceted *community monitoring model*, as opposed to a narrow single approach. A *bureaucratic monitoring* model has the capacity to be much more effective due to its multiplicity of methods for monitoring and the probabilistic advantage this creates for detecting and responding to worrisome matters affecting people's well-being. Proper community monitoring systems are safer providing a climate is created whereby ordinary citizens, staff, family, neighbours, acquaintances and others feel they can step forward with information pertinent to the well-being of persons with impairments.

Investing in people is the key to creating good quality supports as it will be people who turn the hopes for quality into practical action. This task is not particularly easy as it involves finding the right people for many roles, providing them with a sense of purpose, education and technical

assistance, and good guidance. This also applies to people in the crucial external roles of advocacy, monitoring and community involvement as they are the ultimate guarantor of quality and security. Independent individual advocates are essential

The combined community and governmental *system* must anticipate and provide for partnerships at the level of ordinary citizens, service users and families as to ways in which services and the system can work with them. The tendency of professionals, agencies and governments to hoard control over authority, resources and decision-making must be offset by strategies of operation that are more authentically collaborative and which actually share authority and resources with the otherwise "small" people who have lacked access to these advantages. To achieve this within governments the powers of the central system must be decentralized; regional planning, priority setting, budgeting, service development, monitoring experimentation and intentional safeguards should be localized. A similar process needs to be attempted within private agencies to bring authority, decision-making and resources under the direct influence of those people who must rely on services.

The practice of creating targeted individualized safeguards at the level of individuals is hugely helpful for ensuring vulnerabilities associated with particular people are attended to thoughtfully. It is necessary to identify how this may be done properly and who will normally have responsibility for ensuring that the needed actions are taken.

In this as in most other matters related to quality and the well-being of the people served those involved people will need help converting the system to a personalized system. This will be aided as there are created more examples of worthwhile consumer and family governed services.

Such a personal support system must recognize cultural, linguistic and ethnic diversity in its practices and in particular in recognize the many ways in which minorities struggle against the many disadvantages that come with social devaluation, stereotypes, and indifference. This is not a matter of espousing the proper sentiments though some manner of practical consciousness of these matters would be very helpful. More helpful would be an ongoing effort to both raise understanding and change practice.

PART B & C: <u>WHAT QUESTIONS MUST BE ANSWERED & PLENARY DISCUSSIONS</u>

The following are the recorded *flip-chart* notes on the issues and concerns raised with Dr. Kendrick.

Key Questions

How do you provide safeguards? How do you guard against misuse? e.g. conflict of interest

- balance conflict through principles, advocacy, individuals freedom
- struggle with conflict
- now consumers and families have no standing
- shift balance to freedom
- wrong choices can be negotiated

How will this shift affect the system today?

- power moves to individuals
- bottom up
- there are limits

What about risks if something goes wrong with our "informal" systems?

- it's not approval, it's interpretation that matters
- education, training & analysis-informed decisions
- under pressure, government, may rush to decisions B less likely with true partnership

Will you outline multi-year strategy?

- no
- adopt report in principle
- put resources into support and thoughtful implementation
- 5-10 year period of implementation
- several models already working in NS

How prevent delay, inaction?

- don't count on system
- count on organizing the advocacy

How can we make sure new legislation is on track?

- give me your recommendations ASAP
- this will be part of his report re Homes for Special Care

also

- social assistance cutbacks are limiting people's residential choices - less $ for rent equals more struggle
- stronger partnership with consumers, families, advocates
- we all have responsibility for advocating change
- my recommendations are not what's most important - what you do with the recommendations is most important
- don't keep good things secret

Are there models of community monitoring?

- governments could decide everyone should have an advocate (including paid, unpaid) precedents exist (Legal Aid), advocacy programs
- also precedents for community monitoring; e.g. reporting of child abuse make existing legislation more effective
- educate public
- enlarge the net
- family and friends perceive problems first

What about mental health consumers on the streets?

- vast majority of people de-institutionalized are not abandoned
- those abandoned are very small percentage but highly visible
- you can be abandoned while served
- targeted approach
- aggressive outreach to those persons who are refusing support

What are concerns about minimum standards?

- quality avoidance
- emphasizing rigid standards = worse conditions
- don't improve safety; only good judgement does
- hire judiciously
- credentials don't necessarily = quality
- those who live with decision should be part of it
- hire for attitude; train for skill

How will implementation occur?

- stop doing *placements*
- focus on lifestyle support not fixed placement
- unfreeze current system and reconfigure e.g. hosting system with agencies; bureaucracy gets involved on a negotiated basis when needed - local examples: MRCIL, SSG, family cash-based support for youth.

Doesn't this threaten jobs?

- no - just as many jobs
- high morale of workers in flexible arrangements
- relationships of worker to consumer changes
- several ways of providing consumer family with $ for care - need to be personalized and flexible, based on individual need
- give $ to community
- favours negotiated, fluctuating rate

In self-directed programs, who is employer?

- at MRCIL employer is the consumer
- you could have *hosted arrangements* with an agency taking over payroll, taxes, hiring and firing

  education and support needed for consumers to become empowered employers

How do we stop personalized support from becoming standardized?

- advocacy
- clarity of purpose
- value-based education
- decentralization

APPENDIX A

The following individuals participated in the July 17 Workshop

Beverly Wicks
Regional Residential Services Society
Hilary Wellard
Metro Resource Centre for Independent Living
Karen Murphy
Gerald Harding Memorial Society
Deanna Currie
Gerald Harding Memorial Society
Liz Dakai
NS Association for Community Living
Graeme Fraser
N.S. Association Of Social Workers
Gwen Rolls
Nova Scotia Hospital
Joan MacDonald
CCW
Carol Ann Brennan
Regional Residential Services Society
Jane Crawly
CBBCHA
Frances Duffy
Regional Residential Services Society
Connie Jarves -Dennis
Metro Community Housing
Amber Gannon
People 1st Nova Scotia
Catharine Grant
People 1st Nova Scotia
John Cox
People 1st Nova Scotia
James Baltus
Support Services Group
Debra Leigh
Continuing Care Association NS,
Murray Kirkpatrick
Queens Association for Community Opportunity
Helen McNulty
DASC Industries
Mary Pratt
Anchor Industries
Susan Cameron
Department of Education
Hilda Stevens
Sunshine Personal Home Care
Misty Hancock
CLAS
Denna Renney
CLAS
Penelope Kitchen
Metro Resource Centre for Independent Living
Charleen Ades
Tantallon
Doug Campbell
MCHA
Kevin Murphy
Metro Resource Centre for Independent Living /Canadian Paraplegics Association
Barb Dacey
Metro Resource Centre for Independent Living
Lynn Wilson
Neighbourhood Living Society
Lois Wightman

Amherst Small Options Society
Anna Larkin
44 Hazelholme Drive
Mary Rothman
Nova Scotia Association for Community Living
Carol Ann Melanson
Susan MacDonald
Port Hood Small Options
Judy Hickman
Truro Support Services Group
Marlene Weaver
Society for Treatment of Autism
Barbara Aikman
Support Services Group
Sarah Hergett
Support Services Group
Peter Gillis
Support Services Group
Tom Coffey
FAS/FAE Support Network (SSG)
Elsie Cholette
NS League for Equal Opportunities
Judy Marchand
Louisdale Community Homes
D. Van der Baaren
Support Services Group
Marilyn Garrest
Anchor Industries Society
Lois Miller
Metro Resource Centre
for Independent Ltd.
Alana Brown
Opening Doors/MRCIL
Barb Horner
Halifax Association for Community Living
Trent Coady
Jacqueline Samson
Isle Madame Small Options
Agnes O'Neill
Regional Residential Services Society
Joanne Bangay
Shelbourne County Adult Workshops
Marty Wexler
Community Living Centres, Inc.
Charlie MacDonald
Disabled Persons Commissio
Julie MacLean
Conway Workshop Association
Barbara MacLennon
CBW Community Actio
Margot Parker
Metro Resource Centre for Independent Living
John Brown
CACL